HBRP | Healthy Balance Research Program

Priorities for Caregivers: Executive Summary

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A community alliance for health research
on women's unpaid caregiving.

Priorities for Caregivers: Executive Summary

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pour la santé des femmes

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An Urgent Need for Action on Caregiving

Nova Scotia faces an urgent need for action in support of caregivers, since population aging brings with it an increase in demand for caregiving while the supply of potential caregivers is declining, both because of lower fertility rates and out-migration of younger people.

Nova Scotia's government is ready to act, as illustrated by the launch of its Continuing Care Strategy. The research results and policy recommendations made in this paper fit with the goals of that strategy. The findings and recommendations from the Healthy Balance Research Program can inform and assist governments, employers, service providers and civil society in supporting caregivers and care recipients throughout the province.

Context: Women and Men as Caregivers

Women are more likely than men to be caregivers for children, dependent adults, aging parents and parents-in-law, and intimate partners. Men are more likely to confine their caregiving to an intimate partner. As well, women are more likely to perform personal care and other intensive and frequent kinds of caregiving, while men are more likely to help with managing care delivered by others and with home maintenance. Nevertheless, a significant minority of men self-identify as caregivers. It is important, therefore, for policy and program initiatives to be responsive to the needs of both women and men involved in caregiving. Insofar as caregiving is a new role for men, it is important to support their increasing participation in this role, rather than entrenching caregiving as something women are "naturally" going to do.

Background: The Healthy Balance Research Program

The Healthy Balance Research Program, funded as a Community Alliance for Health Research by the Canadian Institutes of Health Research, brought together researchers, caregivers, civil society organizations and policy staff to work toward a comprehensive picture of caregiving in Nova Scotia. The Program aimed to make a difference in the lives of Nova Scotian caregivers by identifying both problems and solutions. The Program's commitment also included the ongoing participation of women from marginalized groups: African Nova Scotians, Aboriginal women, women with disabilities and immigrant women.

The Healthy Balance Research Program funded both quantitative and qualitative research. The quantitative research included analysis of secondary survey data, including the General Social Survey (GSS) 2002 and the National Longitudinal Survey of Children and Youth. The second stream of quantitative research involved a two-phase survey of Nova Scotians, to provide population estimates of the prevalence of caregiving in the province, and then to provide more detailed information concerning intensity, duration and impact of caregiving on women and men who are involved in this work.

Qualitative research involved two major projects: one gathered focus group data from 98 caregivers across the province, with attention to the equity groups mentioned above. The second project delivers "snapshots of caregiving" through 14 intensive case studies of caregivers, where researchers spent 24 hours with each household to garner a more fine-grained understanding of the caregivers' work, problems and rewards.

Principles for Caregiving Policy

Principles for caregiving policy and programs were identified by a 2001 national workshop co-hosted by the Healthy Balance Research Program, and by the Policy Advisory Committee struck to develop this report. Six principles are proposed:

1. Gender equity in policy and programs is necessary as women and men, particularly in marginalized populations, experience different employment, financial, social and health challenges as a result of providing unpaid care.
2. Respect for diversity and recognition of the challenges faced by racialized groups and other marginalized people must be addressed in programs and policies.
3. Attention to family structures and community dynamics is key to informing programs and policy.
4. Unpaid caregiving is a public responsibility with the best possible outcomes resulting when shared by government, employers, communities, families and individuals.
5. The needs of both caregivers and care recipients are central to developing responsive program and system supports.
6. Providing options and opportunities for choice is key to the diverse health and well-being needs of caregivers and care recipients.

Themes and Recommendations

Four major themes emerge from our research:

- Information and Navigation Resources
- Health and Respite Supports
- Transportation Assistance
- Economic Supports

INFORMATION AND NAVIGATION RESOURCES

Caregivers from all communities and backgrounds expressed concern about gaps in existing supports for unpaid caregiving and the difficulty in finding out what supports they are entitled to. As assessment and eligibility criteria become more complex and less transparent, with highly targeted programming, citizens face greater difficulty in learning what services are available to them. First Nations women face inconsistent service depending on whether they live on or off reserve. African Nova Scotian women face barriers in getting information, particularly in rural communities. Immigrant women commented on the lack of culturally appropriate care and difficulties resulting from language barriers. Caregivers with disabilities found difficulties in finding out about accessible services and accommodations in a reliable manner.

We Recommend…

A Care Navigator System

A Care Navigator System would create a point of access for individual caregivers and communities, linking them to a coherent service network responsive to gender and equity concerns and providing ready access to programs and services. Care Navigators should be positioned in communities throughout Nova Scotia, recruited to represent the diversity of people in their communities. Care navigators must have thorough knowledge of the full range of services both caregivers and care recipients need. They must have trust and credibility, cultural competence and a compassionate understanding of the needs of caregivers. Care navigators could work from community agencies or from the formal healthcare system. It is important that face-to-face contact with caregivers be enabled. The Internet and toll-free numbers are a great help to many; however, they cannot replace personal contact and help in difficult situations, from someone with first-hand knowledge and skills.

Education Supports

Caregivers have a wide range of education and training needs to support the important work they do. Workbooks, videos, or web-based modules that teach specific caregiving skills would be helpful to many caregivers. Safety information for falls prevention, safer lifting techniques, the use of and access to assistive devices, nutrition information, oral and personal hygiene, medication management, first aid: all these are elements of potential workshops and videos. Materials should be made available in a variety of languages.

We recommend a central resource to disseminate information and training materials as well as to coordinate and facilitate access to professionally facilitated workshops and peer-education for caregivers. Mechanisms such as Prior Learning Assessment and Workshop accreditation are promising models for allowing caregivers eventually to transfer their skills to the paid labour market.

HEALTH AND RESPITE SUPPORTS

Caregivers reported significant health impacts. About 20% of the survey respondents reported a range of physical and mental health challenges, including physical injury, sleep deprivation and high blood pressure, as well as stress and feelings of hopelessness. Negative

health consequences increased with intensity and duration of caregiving.

The negative impact of caregiving was strikingly different for mothers and fathers of children with disabilities. While mothers were similar in self-rated health to a daily smoker, fathers reported no such impacts. Such mothers are among the caregivers with the most urgent needs, particularly for regular respite.

Stresses and strains of caregiving are particularly notable for women caregivers in rural communities, low-income women who give care, and for marginalized women. Programs like Home Care are intended to relieve some of the stress and strain for the most vulnerable caregivers. Yet, caregivers have concerns about home care, including the inconsistency of workers' skill levels and cultural competency, privacy issues in small communities, frequent turnover of workers and scheduling problems.

We Recommend…

Adequate Levels of Respite

The great majority of caregivers get some support, but only two-thirds have someone who will take over their duties from time to time. Many caregivers are not aware of existing respite services, and some find it too short, too expensive and not frequent enough. Without regular respite, caregivers cannot be expected to maintain their own health, and many other measures, including health promotion efforts, will remain less than useful to them.

Service Improvements in Home Care

Service improvements in Home Care include improved scheduling, greater flexibility in what the worker will actually do, improved cultural sensitivity and competence, and attention to the interpersonal skills of workers. Too often, the caregivers walk a "tightrope of diplomacy and humility" in asking for services to which they and their care recipient should be entitled.

Health and Well-Being Supports

A province-wide health promotion strategy for caregivers should address issues such as nutrition, exercise, stress management and other dimensions of self-care. Support resources such as support groups and counseling should be integrated with the Care Navigator model and educational materials suggested above.

Self-Managed Care

All legally competent care recipients should be able to develop their own care plans and to arrange and administer services and supports that meet their needs. Self-managed care should allow payment to either family members or outside providers or some combination of these. However, self-managed care is no panacea. Many potential users of self-managed care comment on the difficulties of recruiting and retaining qualified staff, an area that requires further consideration.

TRANSPORTATION ASSISTANCE

Transportation problems are major issues for caregivers and care recipients with disabilities and health limitations, to the point that needed medical care is postponed or simply never obtained because of travel costs and other travel difficulties. As well, transportation issues arise for caregivers whose care recipient has been placed in long term care facilities at a distance from their home community.

We Recommend…

Inexpensive and Reliable Transportation

Accessible, available and affordable transportation is essential in both urban and rural communities, not only for purposes of health and social care, but also to maintain the integration of caregivers and care recipients in the community. Urban accessible transportation systems should be extended, with longer hours of service. Community-based transportation systems should be of high priority in small centres, and include service to the Metro area as required for medical and other appointments. Work on such transportation improvements should proceed in parallel to the development of other elements of the Caregiver Strategy for Nova Scotia.

ECONOMIC SUPPORTS

Some unpaid caregivers sacrifice employment, while others balance the multiple roles and responsibilities of caregiving with paid work. Women were far more likely than men to leave paid employment for caregiving—22% vs. 11%. Not only income is lost with employment cessation: health insurance, Employment Insurance benefits, lower contributions to Canada Pension or other pension plans occur. Among those continuing in paid work, many report a lack of flexibility by employers and negative attitudes toward those involved in caregiving who need some accommodation. The challenges of balancing work and caregiving are greater for women because they tend to have lower incomes, are more likely to be in various forms of precarious employment and thus are more likely to have no access to employer-sponsored benefits.

We Recommend…

Income Supports

Direct Compensation involves payments and subsidies to caregivers to compensate for the costs of caring. Medical devices, mobility aids, extended health insurance, transportation, special diets, home renovations and pharmaceuticals should be considered for subsidy or cost coverage. Pension top-ups and the inclusion of caregivers as potential payees for self-managed care are other possibilities that should be considered in the development of a Caregiver Strategy for Nova Scotia.

Indirect Compensation could include refundable caregiver tax credits that do not compromise pension, Old Age Security or Guaranteed Income Supplement payments. A caregiver dropout provision in the calculation of Canada Pension Plan Benefits should be instituted.

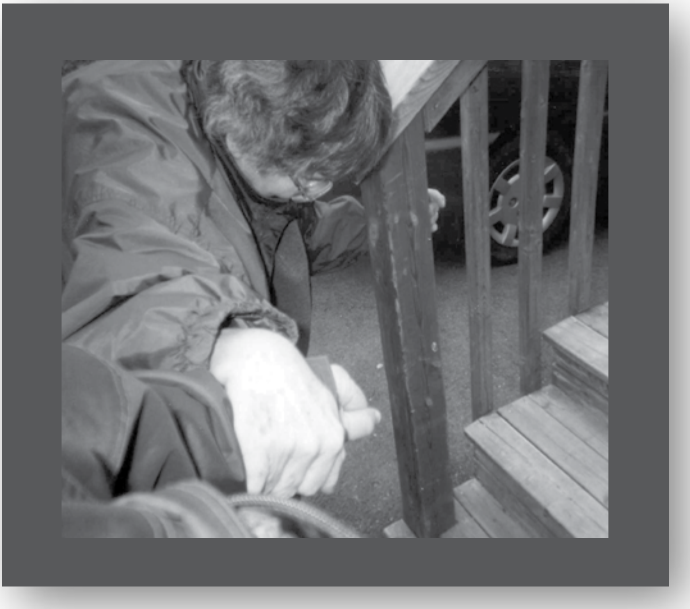
Employment and Workplace Supports

The Government of Nova Scotia should amend Labour Standards to support employees with caregiving responsibilities. At a minimum, the Labour Code should provide for caregiving leave up to a year. As well, the Province should encourage the development of Healthy Workplace programs that include accommodation of caregiving, with tax incentives for employers who do so. Finally, part-time employees should be eligible for employer-sponsored benefits on a pro-rated basis.

At the federal level, there is an urgent need to amend and extend the Compassionate Care benefit under the Employment Insurance program. The length of time the benefit is available should be extended to one year, and the situations in which caregivers are eligible for the benefit should be broadened from palliative care alone. Ways should be found to extend this benefit to persons currently not eligible for Employment Insurance, such as the self-employed.

CONCLUSION

Supports and services for caregivers are urgently needed. Such supports and services need to be accessible, equitable and flexible enough to respond to the wide diversity of needs among caregivers. This document summarizes responses to the research results of the Healthy Balance Research Program. The contributions of hundreds of caregivers around the Province, the insights offered by the Equity Reference Groups, and the work of our research teams give Nova Scotia the opportunity for evidence-based policy making that will confer a national and international leadership role on the province. We encourage ongoing attention to and action on these important issues.



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